Making a Measurable Difference: Moving Data Into Action Transcript

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So first, let me acknowledge a critical co-author in this effort. I don't know how many of you know Magda Peck. Is anybody from the University of Nebraska Okay. Well, Magda is in maternal and child health. And she's a CDC funded grantee. I heard Magda speak at a CDC meeting and it just knocked me out. I was so impressed with her use, this whole process she's developed called the Data Use Institute -- of how to use data to motivate action, that I immediately called her up and said, would you work with us at NCI Which is again, another example of interagency collaboration. She did. She came. She spoke at the Special Populations Network Cancer Control Academy. She helped put together a presentation. And I've adapted that presentation for this meeting because I really think this is a critical element. As Harold said, you can just go blind, and it doesn't move anybody to look at tables of numbers and reports. I mean, we've killed more trees in the interest of cancer control, and done very little, I'm afraid, with some of the reports that we have produced. But what we really now need to figure out is how to move data into action.

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And so Magda talks about, sort of, the three critical things that you need. The leadership issues you need for moving data into action. First is to think about it. And that's what you all have been doing. You've been doing it before you got here. And you've hopefully been doing it while you've been here. And I would just say that the number of questions that we're getting, the thoughtful ideas and questions we're getting, suggest that you have been doing a lot of thinking, which leads to knowledge. But as Harold said, if that's all we do -- if all we keep doing is thinking about this and studying it, that is not sufficient. That we really now begin to need to act, and above and beyond what we can do ourselves, we also have to influence others, enabling others to act.

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And so here are the keys that Magda's identified for translating data into action. The first is that you have to build data use capacity within communities. We've already seen that many of the missing pieces of this puzzle are local data issues. Information that tells us about our special populations may not be well reflected in national surveys,

even in regional surveys, even in the state BRFSS data, which is a state sample, but doesn't necessarily help you understand what's going on within a county. And even though you can collapse data across years, there are sub-groups within those counties that are hard to get at because the numbers are too small. And those samples were never designed to answer those questions. So building capacity may be one of the issues and it was on your map. There was a whole section on surveillance. That may be an issue that you are going to want to think about. Collaborative team-based training works best. Everybody has to be involved in thinking about data use. It's not just the state epidemiologist who should be telling everybody else what to do with their data. Everybody has to be sitting at the table talking with each other and figuring out what is the story in this data. How does it apply to me And how can we use it to motivate change Public health agencies must provide leadership for cancer control data use. State and local health departments and their relationships -- CDC has created enormous resources to help support this activity. They are the leaders in trying to pull the data together, but the community has to be involved sitting at the table saying, these are the data we want to know. This is what's going to help us do our job. If we don't have that data, how do we get it And then focus on participating institutions' data use. Everybody has got to be a master of data use. Nobody can be sitting on the sidelines and saying, just tell me what to do; I don't want to know about the data. That's not going to work. Everybody has to feel comfortable if they understand what this data means. Now those are the keys. Here are the challenges. If I know it, it will change. Forget it. That is not going to happen. Knowing things is not enough to make change, but there are people who believe that. Nobody here, I'm sure. If I'm doing it right -- if I'm already doing it, it must be right. We have programs that have been out there for a long, long time, absolutely certain that what they've been doing is exactly what needs to be done. Here's the problem. We have fifty years of these mortality disparities. Yeah, you've been doing it for 20 years. We haven't eliminated it. There must be something we can do differently. But that's a problem. If people have been doing things for a long time, it's very hard to get them to think there might be something that they could do differently. And then finally, if I'm already right, why do I need to hear any more from you. So these are really hard challenges to overcome. This is the institutional inertia that exists at every level of our communities and in government. And this is the kind of forces that you are going to have to overcome.

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So, as Magda says, by aligning these three things, you can make change happen.

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Now here is just a little smattering of some of what we've learned. And this is the slide that Carol Kosary presented that showed that despite the sort of reduction in incidence, there's been a flattening out. And this concerns her, and I think it should concern all of us. With the exception for the 65 and older group, there's been a flattening out of the incidence of invasive disease, which sort of plateaued here, and that's a concern.

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The mortality rates have been coming down, and that's the good news.

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But the news that we really have got to get out into the communities is despite that overall reduction in mortality, we have these long-standing, consistent patterns of cancer mortality that exist.

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We know from looking at, sort of, the urbanicity, is that the majority, but not all, the majority of the counties in these high risk areas -- and this is for whites, are either rural or either suburban counties. But there are a smattering of urban counties. And the point that somebody made yesterday and Harold picked up on, is that there may be some really critical similarities between inner- city urban communities and rural communities. And that may be an important place where we can come together in the state.

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African-Americans, the same, sort of, long-standing patterns, and again, the majority of these counties are urban and rural.

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I presented this to you at the very beginning of this. I'm not going to go over it in detail. But the question we are now asking you is what we can do With what we know now, what can we do. And one of the things that we may want to do is to find out something more, but that can't be all of it, it can't be just about more research. There has to be some action that needs to be taken at the federal level, at the national level, and at the state and local level, and we need your

advice.

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Now, George, last night, said that he had been hearing this question, and it had really kind of bothered him. And when he said that, I decided that we should label this the Sawaya dilemma. So thank you George. I'm going to be using the slide all over the country so you're going to become famous. And I think George's point is really important, here. Where do we draw the line What do we accept as acceptable Are 5,000 deaths a year acceptable Is that enough Or is it more about how can we use this message Why should any woman in America die of cervical cancer The answer may be, and I forget who said it yesterday -- they don't want to be screened, they want to die. That was an interesting perspective. I'm not sure that that's the message I would use, but it's an important perspective to think about and it certainly speaks to one of the issues that you're going to be struggling with, which is, that there are competing priorities in people's lives. Harold used to tell me this wonderful story about -- . When we first started working on breast cancer screening in Harlem, he made the point that trying to convince a woman who had three jobs, trying to keep her family together, pay the rent, and make sure that everybody had clothes and going to school -- . Trying to get that woman in for a mammogram was sort of comparable to asking a soldier in the middle of a battle with bullets flying over his head to bend down and have a digital rectal exam. And that is an issue. These competing priorities and messages for these extremely hard to reach -- . Did I get that right, Harold I didn't want to misquote you on that. To try and get populations that are struggling with these enormous, everyday life issues to think about Pap smear screening is a challenge. But, we have to ask ourselves, is this a message that will help us address the question of what needs to be done to reduce, if not eliminate. So there are message framing strategies, as Vish said last night, that we need to talk about. So you need to struggle with he Sawaya dilemma.

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Okay. So what else do we need to know We've talked a lot about information that we have and actually Harold and I have obviously been working together for too long, because he didn't know that I had this slide in here, and yet this morning, he made the comment that cancer statistics are people with the tears wiped away. So, I don't know, Harold. We've been hanging out in some strange places, and this might top it. This is an important issue. What I'm going to do now

is ask you to just take a moment with me, because I'm going to read you a story. It's a hypothetical story and it's a story that will be distributed at the end of the session to you, because there's an exercise in it. But just take a breath and let me read this story to you. By the time the priest arrived, Joanne was already gone. She lay on the hospital bed, surrounded by her grieving husband and her three children who had watched her slip away, unable to help her fight the deadly cancer any longer. They had watched each breath become more labored, as one by one, they held her hand to comfort and calm her as death approached. That she was about to die was incomprehensible. With each tug of air and grimace of pain from the metastases, they saw the color in her cheeks fade to gray. As they bore witness to her spirit taking leave, her husband Chris thought back over the past two years and wondered how things might have been different. At 47, Joanne had been in good health. A working mom, she had seen her family physician once a year. While she had smoked since high school, she had been able to successfully quit more than 10 years ago. Joanne had recently started getting a bi-annual mammogram in addition to her annual breast exam at the time of her regular physical exam. However, since menopause, she had stopped getting a Pap smear every three years, which her OB/GYN had always reminded her to get, but which her current family physician had mentioned occasionally, but had not emphasized. While Joanne had not immediately checked with her doctor after she noticed intermittent bleeding and vaginal discharges, when she mentioned them to Chris that she had been experiencing pelvic pain he persuaded her to make an appointment with her OB/GYN to get it checked out. From there it all seemed to go downhill. A colposcopy confirmed a cancer that was so large that radiation therapy was the recommended treatment in a regional cancer center. Travel to and from that center created quite a burden for Chris, Joanne, and their high school son, who could drive. Chemotherapy was presented as a possible, additional, treatment option, but Joanne ruled this out because of her fear of the side effects of chemotherapy. Unfortunately, radiation alone failed to halt the spread of the disease to the other parts of her body. The final year was very hard on Joanne, her family, and her friends. In their profound grief and anger at feeling helpless now, the people who had known this wonderful woman and others who came to know and care about her, asked many questions. Why did Joanne's family doctor not push her to continue, regular tri- annual cervical cancer screening Why wasn't more information available to inform women like Joanne about the

importance of continued Pap smear screening after menopause Where else in the community could she have been educated about and been able to obtain a Pap smear test Why did Joanne keep her bleeding and discharge problems to herself for so long Did Joanne and Chris consider her participating in a clinical trial to test new combination chemotherapy If so, what might have discouraged them from choosing this option Could Joanne's pain and suffering in her last six months I just noticed that there's a type in here. My fault. It says in his last six months, it's supposed to be in her last six months. So please ignore that when you see that or change it of life been managed better . And what kind of support is available for Chris and his children now that Joanne has passed. So Joanne is one of thousands of Americans and patients from your states, who every year develop cervix cancer and die from it. We've already talked about the good news. The rates are going down. But the bad news is that the rates of decrease have been flattening out, at least in terms of incidence, and 50 years after the introduction of the Pap smear, there remain communities, mostly rural and suburban, where women have been and continue to be two to three times more likely to die of cervix cancer than the rest of the U.S. So in your exercise, this morning and this afternoon, you're going to be asked some questions that are on this sheet, and you'll get this distributed to you, about what needs to be done to prevent avoidable cervical cancer deaths like Joanne's and what actions would you recommend and to whom would you recommend them This is very important. How can federal, state, and local partners make a difference in communities in your states And when you're considering all of this, consider the data that you have and consider, not only the information that we have that helps us know what to do, but also consider the information you're going to need to take action and motivate others.

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So, Magda has used stories like this, and she helped me write this one, and talks about the circles of influence and the circles of impact.

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And the critical element to achieve system change is to link these two circles.

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So here are all the forces that influenced Joanne's life and her death. And you can see them spread out here on this diagram.

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The circles of influence are the folks that are as far away from Joanne as possible. The state and national policy makers who don't know Joanne from a hole in the wall. The local officials and policy makers who may or may not know Joanne, may have bumped into her at the mini-mart, but don't necessarily know her as a human being. The health department, the American Cancer Society, Transportation Services. All of these different services spiraling in to those people who know Joanne best. Joanne herself, of course, Joanne's family and Joanne's health care providers, and maybe folks at her work place.

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Now the circle of impact. Now who does Joanne's death effect Well, obviously Joanne. Her family, her health care providers and the folks in her workplace. Maybe the community programs where she used to volunteer. Maybe the American Cancer Society I don't know if they know Joanne. Maybe -- unlikely the health department, as I said local health officials and state policy makers are going to know Joanne anything other than as a statistic. An unfortunate statistic, but that's who she is at that level.

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And so when Joanne dies, this is something you need to think about -- how do we link the circles of influence and the circles of impact Now here are the models that are necessary, but really not sufficient. Magda calls it the bulls-eye model: Let's just focus on Joanne, just tell her story; that's all you need to do. Well, that's not going to work. And if that's all you do, that's not good enough. The smoke rings model, and I think that's a great name because there is, sort of, this vision of blowing smoke somewhere. That's the model that says, let's present all the data to the policy makers and get them to understand that there are lots of people -- we're not going to name them; we're going to tell you who they are; we're not going to tell you anything about them that might cause those policy makers to connect with what happened to Joanne. We're just going to tell you that there are all these statistics, maybe we'll show you the maps. And then there is, kind of a model that tries to connect some of these pieces to the dots, as we do, for example, when the ACS and the CDC and the NCI mob work together. And that's part of it, but that's not sufficient.

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The key is to promote strategic connections between the circles of

influence

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and the circles of impact. So models for systems change involve this.

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You have to take your knowledge base, you have to develop a social strategy. And Vish alluded to this yesterday -- last night, rather. it's really a social marketing strategy. What are the critical messages For which audiences are going to move people to change. And your goal is to get them to develop the political will to make a difference.

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Here is the map you developed. And when you go into your groups this morning, I'm going to ask you to look at all of these clusters, but I'm going to ask you to look at them in a slightly different way than you've looked at them up to now. Start in the middle. This might be Joanne, sort of. Case management and follow-up. Expand screening treatment opportunities. Reach high risk and underserved populations. This is sort of the core of it, isn't it Reaching those that have yet to be reached. Expanding screening and treatment opportunities not for everybody, as George said. I mean, you screen somebody for 28 years and they are all negatives. Why are we still screening that person when they're 68 years old Maybe that's not an appropriate thing. But how about all those folks like Joanne, who stopped screening after menopause, who hasn't been screened in ten or fifteen years -- maybe those are the folks we have to reach. And how do we ensure that when we do reach them, we manage their history. If they have an abnormality, we ensure clinical follow-up. So that's a group that you'll want to think about. And what are the priorities in that group that are going to be important for action Now, of course, I come from the NCI, so I think research is really important. And actually, we've identified that there are a lot of missing pieces to this puzzle. So as you think this morning about what national organizations should be doing, feel free to demand of us things that you think need to be studied. And there have been a number of issues that have emerged, and I'll show you one in a minute, out of your concept map that might be really important for national organizations to consider studying. Obviously, it's going to be critical that when resources are involved, we're going to have to collaborate and develop partnerships to change policy to increase funding and reimbursement. It's not enough to simply say, and I forget who said it yesterday -- "Oh, this is all great if we come we up with these ideas. But where is the money going to come from "

And again, I would want scrap to some B-1 bombers, but I'm not sure that's the social marketing strategy we're going to go with, particularly right now. That might not work so well. But there may be other ways. For example, what are your states doing with the master settlement agreement money from the tobacco settlement Just a question. I don't know. You think about it. And then finally, what is it that we want to do Well you've got a group of clusters here that talk about targeted public education and communication, culturally appropriate education and communication, and improving health care training. There are a whole set of statements in that group that could be critical to what it is you're going to want to do. Hey, I'm right on time; I thought I was running late. Cool.

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So this is the importance and feasibility of all your statements. This is overall, but as you group things into these four, what does Mary say -- She calls them ber- clusters. There's something funny about that statement. I don't know, it makes me a little uneasy.

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Meta-clusters. How about that That's better. As a data person, that's more comfortable for me. As you think about these things,

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think about their importance and feasibility, sort of, in that grander scheme of clusters.

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And let me give you just one example, because, I am again, a researcher . DR. KERNER: There were a number of us who said, "Gee whiz, why didn't people think this was more important " As somebody said the other day, I mean, "God, if we could develop a vaccine and really prevent HPV" for those who have not yet been exposed, of course, and maybe for those that are out of the loop of being infected "wouldn't that be more important " Well, let me just show you the green zone. First of all, you'll notice that there is only one dot that's sort of bordering on the green zone. And there were two -- and I'm going to focus on those first: develop and administer a vaccine against HPV and create a state registry of cervical cytology and histology results linked to clinical information that were in the very important quadrant, but not too feasible quadrant. Now, again, reasonable people could disagree about feasibility, but those are important statements, that, independent of whether you think they are

important or not -- if your group, your region thought it was important, you might say, well, maybe that's a longer term issue that will tell the federal government: "Make sure that's on your radar screen. If it is, great, tell us about it; give us updates about it." But the item that really jumped off the page at me, and it was actually mentioned in one of the summaries. And by the way, the summaries of your comments are where MS. VINSON: We're going to be giving out those at the breakout sessions. DR. KERNER: Right. So all of your report backs -- we were having people. Our science writers were furiously writing them down and at 10:00 last night, we had a surreptitious meeting at the bar where we looked them over and edited them. So there may be some alcohol stains on them or something. But we tried to get all that stuff that you shared with us -- that wisdom that you shared fed back to you. But look at 59: Investigate factors with acceptability of possible prophylactic HPV vaccine among at-risk populations. Now what's the timeline -- Joe, I'm going to ask you. What's the timeline for a vaccine I know it's in testing. What do you think All right. Ten years. That's, probably, for some, very disappointing, but it takes a while to do this. But what if between now and then you demand it of the federal government, of NCI, of CDC, maybe of ACS; I don't know that some kind of survey work will be done to anticipate what the audience's reaction is going to be and what the barriers to delivering an HPV vaccine will be so that when the vaccine was ready, we would already know how to do the social marketing for it. Why wait until the vaccine is available to then start what might take a three to five, a ten year as Ed pointed out, that diffusion curve -- it takes time. Why wait to find out how the audience is going to react to this Why not think about doing some surveys on a hypothetical scenario Maybe buried in some other testing strategies or prevention strategies and try and figure that out. I'm not saying to tell us that. I'm just saying that's an example of how you could use this green zone data to take one of those big clusters, zero in on a critical statement, and this morning, make a recommendation to the national organization. Let me tell you guys, you're never going to get a better chance to tell us where we should and what we should do. This morning is your chance. You're going to be sitting there this morning and focus on what should national organizations be doing. So, the sky is the limit. Now, if you want to tell us to scrap B-1 bombers, that's your choice. There are not too many of the organizations here who have any influence at all with the Department of Defense. But, you know, it's up to you to tell us what to do.

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One of the things that I don't think I've shown you is the discovery-delivery continuum. Harold alluded to the gap between discovery and delivery in the very beginning, and I took that framework that he formulated, and I've developed this continuum that starts on the left and there's no political meaning to that unless you want there to be with research. And of course, we do a lot of research. And we do what I would call passive diffusion. I don't know that I have ever talked with Ev about this, but I see diffusion as sort of having this passive diffusion, active diffusion. A lot of us in the federal government think that when we publish a paper or we present it at a conference, we've done our dissemination job. But frankly, I was once quoted in the National Enquirer from a conference I presented at in Seattle, and my secretary at Sloan-Kettering came running in to say that I was quoted in the Enquirer. I was so embarrassed. And of course, I was totally misquoted, which was probably appropriate. I didn't sue for libel. But years later, somebody pointed out to me that probably more people read that one article in the National Enquirer about what I had said, than anything that I will have written in my whole professional life in all the journals. And that's really an important piece of information to think about. Okay. So one of the things that we need to think more about is: Often we have this inventory of intervention products that we've developed to do research, but then we haven't invested the money in dissemination/diffusion research to figure out how to get it out into the communities. So again, if you're thinking about that sort of bottom part of the diagram, research, maybe dissemination and diffusion research is a recommendation you're going to make. Maybe CDC is going to up its budget for that, or maybe NCI and CDC should be told: We need to collaborate on dissemination/diffusion research. We're already doing it in some ways and we're also working with ACS. What about dissemination We need to do a better job of telling Joanne's story. This has got to be made personal if it's going to touch lawmakers. I've been stunned -- are you all avid fans of C- SPAN Anybody want to raise their hand and admit that No. Oh, okay. A few. Well, I've been stunned by the impact that one compelling story in testimony can make in terms of legislation. Or, what one senator getting prostate cancer can do in terms of legislation and research. It's amazing. With all the reports we've produced and all the science we've put out there, that one story can make more of a difference. So we need to do that and ultimately we have to impact delivery. So think about the factors that relate to inter-agency partnership across the continuum. And help us develop an action plan. That's the critical issue.

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Now this is a model that I presented to Nancy; I've presented it to the American Cancer Society. It's just a cancer control partnership model for three national organizations. And what it says is that each of us makes investment and have different strengths in different areas. We all do everything, but we all don't do everything to the same degree. So NCI most of our money goes into research, extra-mural research. That's what we're good at. We know how to do that. So that's our strength. We're increasingly getting into knowledge synthesis; we publish papers. I'm here; we're going to do more dissemination and diffusion. We're building up teams in all of our divisions. We're working with the new center. But we don't do much direct service. The American Cancer Society, my goodness. They do tons of direct service. They're out in every community. The have volunteers helping people everywhere. They also do dissemination and diffusion increasingly. They fund research and development, and they do knowledge synthesis. CDC and I don't know if Nancy would agree with me but to me, is the pre- eminent dissemination and diffusion agency in the federal government. They have links to every state health department; they have links to community based organizations; they are the masters of dissemination and diffusion. They fund -- they do direct service, they fund the breast and cervical they don't do it directly but they fund breast and cervical cancer screening programs. Other activities -- they're clearly doing knowledge synthesis. We're working collaboratively with them. And they have a relatively small research and development budget. So we all have different strengths. The model is -- how do we work together to make those strengths address this problem, and we need your advice about that. But some of you may be sitting there saying, "Well, wait a minute. This isn't the whole universe at the national level." What else is out there Well, how about CMS How about HRSA How about the Indian Health Service How about the U.S. Department of Agriculture, that has this cooperative extension system in every county in America Can they be brought into this process People use the term, think outside the box, and it began to irritate it, but I'll use it now. Think outside the box. How do these federal agencies collaborate together What is it that you want us to do differently than we're doing now that would help you ultimately at the state and local level

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And then finally, as I said before, using data to change policy. It's not just a clinical intervention delivered in one community. There are policy issues here. How do you turn this opportunity into action And

it's the same set of issues. What is the data telling us How do we develop a social marketing strategy or a campaign strategy -- dare I use that term And how do we change the political will.

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And as I said earlier, the bottom line here, is, we have to do it at the national level; that's what you're going to be focusing on this morning. We have to do it regionally. And we've divided you up into regional groups that I'm about to tell you where you are going. Although, Cindy, I will notice that the one group that is not on this list, which, I guess, isn't a regional group, is the federal group. So all of us at the federal level need to be told where to go. (Laughter). SPEAKER: I'm sorry Jon. DR. KERNER: That's all right. I knew you'd like it. We're going to be working together at the same time as the regional groups are to talk about what we can do at the federal level to work together. And then finally -- and let me just mention that maybe there are ideas that will come of multi-state collaborations. This has been working you know. There's been all sorts of interesting examples of policy change that have been generated by states working together. Maybe that's something that you're going to want to think about. And then at the state and local level -- what can you do So that's really all that I had to say to day, except that Joe is going to remind me that I forgot something else to say. DR. HARFORD: I just have a recommendation. DR. KERNER: Okay. DR. HARFORD: That is, can you change the name of the federal group to the national group DR. KERNER: Yes. You're absolutely right. And I'm sorry. That's quite right. In fact, that's what I was supposed to say, but you did ask it in the form of a question. Yes: "Could you do that " It's okay, we will accept that answer then. But no, that's right. It is national; it's not federal because, although the bulk of the people here are from federal agencies, we have national ACS and Local ACS representation. So we hope that the national ACS office people will join the federalists. And remember, we are not about federalism; we're about Friedellism . Okay. I want that burned into your mind. How can we help, at the national level, to support what's happening at the state and local level. So let me stop there. If you have any questions or comments, my friend from Indiana is going to give it to me again. Go ahead.